

IMMUNIZATION REGISTRY FOCUS GROUP STUDY

September 14, 1998

Non Hispanic white, Lower Education

Ankeny, Iowa

Moderator: Wendy Child

SECTION 1: GENERAL IMMUNIZATIONS AND HEALTH CARE

I. Prevention

Participants mentioned the following as diseases they are most concerned about:

- Hepatitis
- Smallpox and other diseases that are “coming back”
- Cancer
- Diseases from terrorists’ chemical weapons

Comments included:

I think hepatitis [concerns me the most]. I think it's B isn't it? I think the schools and everybody pretty much talks to kids about the hand washing and we can't bring any cupcakes or anything like that.

They had in the paper a couple of weeks ago how the terrorists could leash some germ on us. That really bothers me. I didn't like that at all. And I always think of my kids – it's them I worry about.

II. Immunization

A. *Reasons not to get vaccinated*

- Allergies
- Side effects, especially from chicken pox vaccine

Comments included:

I think some parents are scared because there is a chance when you get the vaccination, you can get the disease.

I've heard stories where children have gotten really sick from the vaccines and I don't know if they died from them or what.

B. *Reasons to get vaccinated*

- Protection against diseases coming back
- Vaccinations are required to go to school
- For peace of mind
- Preventing outbreaks of disease

C. *Ways parents are reminded of vaccine schedule*

- Schedule card provided by hospital at birth of child
- Doctor calls or sends reminder
- Next appointment is set up during doctor visit
- Record book that the doctor fills out during visits

Comments included:

There's a little card that says this one is due at this time.

I know they'll send out a message or a note to us and say, 'He's due on such and such a date for a shot.' We have a book they write in that they've had this shot.

It's crucial to have the card because if you lose that card and you have no record, they can [give the shot] again -- do the whole thing over again.

D. *Methods of easier tracking*

Parents could not offer other methods than those already mentioned (i.e., schedule card and record books).

SECTION 2: IMMUNIZATION REGISTRIES

I. *Initial reactions to the idea of a registry*

- Most of the participants were unsure of why the registry is necessary. They noted that they keep track of their children's records and that records can be transferred from doctor to doctor if they move.
- A few people thought the registry might be useful in an emergency for determining quickly if a child had had a tetanus shot or for finding out about newly recommended vaccines such as for Hepatitis B and rotavirus.
- One person wondered if participation would be voluntary.
- Only one person seemed to object fairly strongly. He was concerned about what would happen to people who might decline or be unable to afford to have their children immunized and whether there would be any discrimination against them.

II. *Content of the registries*

A. *Initial reactions to the type of information typically in a registry*

- Participants liked that the lot number of vaccines would be included.
- No one indicated discomfort about any of the information typically in a registry, but a few people asked about who would have access to the information.

Comments included:

What caught my mind would be the lot number because if your child did have a reaction and you need that lot number and other children that had that same lot number were having that type of reaction, maybe there was something wrong with the vaccine. We had that flu vaccine...and they said certain lots of it weren't strong enough.

I'm going to ask my pediatrician to [write down the lot number].

I wouldn't care to have my name published.

B. Reactions to including home address and phone number

- Most participants seemed to be concerned about having their home address and phone numbers included. However, one person said:

We're talking about immunizations here, are we not? Why would we care if it doesn't have your phone number? Why would you care? I can't think of one person, be it friend or foe, who would want to look at my children's immunizations.

C. Reactions to including parent or child Social Security number

- Participants were similarly negative about the registry having their own or their children's Social Security numbers.

D. Reactions to including healthcare members enrollment identification (WIC, Medicaid numbers)

- Participants thought it would be acceptable for this identifying information to be included.

Comments included:

I think if I was in one of those programs, it wouldn't bother me.

I'm assuming if you knew what the criteria is for [those programs] the rest is just public knowledge anyway.

III. Access

A. Who should have access

- Health care providers
- Hospitals
- Doctors' offices
- School nurses
- Maybe insurance companies

- A few people wanted reassurance that access would not be available to everyone at the doctor's office or hospital. They said:

Who in the health care provider's office [would have access]? In a hospital, there are so many people. I wouldn't want to think that just anybody could go into their computer and pull that up on my kid just because they'd want to see it.

As far as the receptionist who sits at the front desk, she really wouldn't need to have access to that kind of information.

The staff that takes care of the records now would have access because they're the ones that would [take care of] a request that came in...If you went in and said 'I want a copy,' it's going to be them who handle the files now.

B. Who should not have access

- Participants thought that no one outside the medical field should have access.
- Participants seemed uncomfortable about public health researchers having access to the registry data. They could not envision a good reason for this. Comments included:

Not unless they wanted to take a poll and see how many parents were up to date.

That's the only information that I think they would want.

C. Reactions to the idea of linking registry by computer to other health information systems

- Participants were confused about what purpose would be served by linkages between registries.

Comments included:

I don't see what the connection is. If they were getting like a shot or something to lower lead in their body, then they would have to know that [maybe].

IV. Consent and inclusion

A. Reactions to "opting out" option

- Participants were concerned about this option because of the potential of parents not realizing that they had been notified due to lost or mis-delivered mail or forgetting that you received it. One person commented that this option might be acceptable if people were notified by some means other than mail (e.g., by phone or at the doctor's).
- Participants agreed that this option would be the easiest for states to administer.

- Some participants thought that they might opt out on the basis of information presented in the focus group. They said:

I think I would [opt out]. I would at least until I found out more information and maybe let everybody else see how it went before [I participated]. I'm sure I could always join it whenever I decided, but I don't think I would do it right away, no...unless they could guarantee me in writing who was going to have that information, then I wouldn't want it.

I think personally I would opt out because the people who are really in need of this information are myself and my doctor. Why would John Henry sitting up in the Lucas Building need to know if my kids had their shots or not?

Other comments included:

I just think we should be given the right to decide or not. I mean, it's our child.

It's not OK unless you say OK.

I think everybody should be allowed the choice whether or not they want to participate. Either they do or they don't and with this one, it does give us a choice, but it gives us a choice in a backwards type way.

Anything related to my children, I want to be able to give consent...I want to be able to say, 'Yes, you can' or 'No, you cannot.'

B. Reactions to “consent” option

- Most people thought that this was the best option.
- A disadvantage would be that parents who do not immunize their children would not consent and even parents who do immunize might not take the time to sign the consent.

C. Reactions to “automatic” option

- Participants were very concerned about this option. They said:

I would move [if they did that here].

That's too controlling. That's telling you you don't have the option. It's like saying you have to spend the rest of your life in this room...It's going to start there and go somewhere else.

It's not really about the immunizations. It's about all the other information. That would mean that anyone can go in and say, 'You know, we're going to pull up [name of participant's child]'. If it was just vaccines and it didn't have date of birth or name, then it would be OK. I mean, you don't know who's out there.

SECTION 3: WRAP-UP AND CLOSING

I. Most important benefits of registries

- Might make sure everybody's children are immunized
- Access to the lot number and company that made the vaccine
- Convenient source for copy of information if you lose your own records

Comments included:

I think the only good benefit would be to make sure everybody's children were properly immunized.

I did like if I could get access on the lot number and the company if there was something wrong and also if my doctor's office had this and I lost my card, I might get a copy. If they could – boom – get me a copy...push a button and print it out and I'd pick it up.

The big benefit would be the company and lot number. If there was a problem, then you'd know who to contact.

II. Greatest concerns/biggest risks

- Privacy concerns if name, address and other identifying information is included. (Some people recommended that an identification number unique to the registry or the same as the doctor's file number for the child be used.)

III. Influence of healthcare provider in decision to participate in a registry

[This topic was added to the guide after the group, but one person volunteered in her closing comments that she would ask her doctor if he thought that participation was necessary. Her comment is included in the next section.]

IV. Suggestions/comments to people who are responsible for how system works

- Participants' closing suggestions and comments included:

...I would want to give my consent at the doctor's office and I wouldn't want any personal information included.

I think if I got it in the mail, the first thing I would do is show it to my doctor and see how he felt and see if he thought it was necessary.

If it was just immunization information and there wasn't any other [data] like my name or other family history, I wouldn't have a problem with it.

I thought [it's OK] as long as they keep the access [limited] to health care providers.

I definitely would need more information and then I probably wouldn't have a problem with the registry but I would like to be able to make up my own mind on what's on it and also, I don't think my child's gender should be on there...My name, I wouldn't mind...